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Commentary: enabling good emotional support for and with people with learning disabilities

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3 People with learning disabilities have traditionally been assumed not to have the
4 same depth of emotional understanding or insight as other non-disabled people
5 (Hardy and Bouras, 2002). Their subjective experiences have been largely seen as
6 secondary to their behaviours, especially their 'challenging behaviours' (Heyman *et*
7 *al.*, 1998), with psychological approaches focusing on the observed 'externals' of
8 behaviour, rather than the internal emotional distress which might be experienced.
9 Arthur (2003) provided a useful review which redressed that problem, and called for
10 a greater understanding of the 'emotional lives' of people with learning disabilities.
11 Such an understanding is of course very much part of what it means to be valued as
12 'human'. With current theory and research again reflecting abuses in services which
13 devalue people's lives (Bubb, 2014; Heslop *et al.*, 2013), there is still an urgent need
14 to consider the shared humanity and emotions of people with learning disabilities. To
15 that extent, the previous article by Cotter, Hollwey and Carr on the transference
16 process between therapist and client reflects a much needed emphasis on access to
17 talking therapies for people with learning disabilities (Taylor *et al.*, 2012). It highlights
18 that the 'transference of emotions' is simply a human-human process, whereby we
19 recognise that everyone is affected in a therapeutic relationship, and where we
20 accept that people with learning disabilities have a part to play in affecting the
21 emotions of others.
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35 Nevertheless, despite this welcome focus on emotionality, it can be argued that the
36 medicalization of mental health can itself be a problem for people with learning
37 disabilities. Their mental health support is often considered within the framework of
38 'dual diagnosis', where not only the mental health issue, but also the learning
39 disability itself, are seen in a sense as 'illnesses'. Williams and Heslop (2005)
40 presented some views and reflections from a project with young people in Somerset,
41 in which it was suggested that mental health support needs could be created by
42 social factors; in effect, this was not so much an argument for the social model of
43 disability (Oliver, 2013) as for a social model of impairment (Hughes and Paterson,
44 1997). Whatever the case, the argument presented by Williams and Heslop (2005)
45 was based on the common experience of people with learning disabilities with whom
46 both authors had worked in research and residential support. A colleague with
47 learning disabilities once said to the second author that he had an appointment with
48 a psychologist, and when the team enquired why, he said that he was upset because
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3 he wanted to get out more. Staff members where he worked were worried, and made
4 him sign in and keep to strict hours. The solution to this issue did not entirely seem
5 to lie in the diagnosis and treatment of his emotions; it lay far more in some
6 adjustments which were necessary in his support and living arrangements. Happily,
7 these things did happen later on in his life, when he moved to his own flat, with the
8 support which he chose. In short, if people are unhappy because of the
9 circumstances of their lives, we can at least attempt to understand and adjust the
10 social practices which are constraining them, rather than to fix the person. That is in
11 fact the goal of the current 'Getting Things Changed'¹ study, in which a multi-
12 disciplinary team led by Williams aims to theorise how social practices and cultures
13 become unhelpfully fixed, and how they can be adjusted to fit better the varied needs
14 of different disabled people. One of the strands in this study uses Conversation
15 Analysis to examine videos of interactions which take place between people with
16 learning disabilities and their personal assistants. It was interesting that the ethics
17 committee itself in this case (the Social Care Research Ethics Committee)
18 encouraged the team to foreground the views and wishes of the people with learning
19 disabilities themselves. In fact, this part of our project is co-produced with a drama
20 group of people with learning disabilities, the 'Misfits', whose insights and
21 understanding of their own life experience is being brought to bear through dramatic
22 re-enactments of the data.
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37 Not only are living arrangements and 'placements' of people with learning disabilities
38 dictated by an unwritten culture of protection, but also therapy itself is enacted via
39 social and interactional practices. In order to ensure that people with learning
40 disabilities really do benefit from talking therapies, we need to ensure that the
41 practices themselves are made more accessible. This means that more inclusive
42 practices of therapy need to be applied, to meet the needs of people with learning
43 disabilities to explore and understand their emotions. This may often mean deviating
44 away from traditional 'talking' therapies towards more creative ways of working
45 through emotions. Research in the area of bereavement support for people with
46 learning disabilities provides a number of examples of creative approaches to
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53 ¹ ESRC Grant ES/M08339/1 'Tackling Disabling Practices: co-production and change'.
54 <http://bristol.ac.uk/sps/gettingthingschanged>
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working through difficult emotions, such as life story work (Read and Bowler, 2007), and creating memory boxes (Young and Garrard, 2016).

As Cotter, Hollwey and Carr argue, the emotions of people with learning disabilities will have an effect on the therapist and the emotions of the therapist will also affect the individual with learning disabilities. Natural human-human interactions are extremely important to people with learning disabilities and those created within the therapeutic setting are likely to be no different. However, for these relationships to be effective the individual with learning disabilities must feel able to trust the therapist which will involve engaging with their own emotions. It is good to identify the ‘difficult’ feelings therapists may have about working with people with learning disabilities. This might be explored as a mutual issue with people with learning disabilities within the therapeutic context rather than a separate one. This runs counter to what seems to be a deeply-rooted belief that, within psychotherapy, the therapist has to ‘hold’ everything. The discussion around the issue of parental grief and individuals with learning disabilities provides one example of this. There is an assumption here that the best course of action to resolve these issues is to seek therapeutic or psychiatric support and that the therapist or psychiatrist knows ‘best’ in this situation. This is not always the case; seeking ‘professional’ help is not the only option people have for working through their emotional issues, and in our ongoing study ‘Getting Things Changed’, we are exploring institutional barriers created by professional-lay encounters across a wide range of social contexts. Our research is co-produced with disabled people, and we are aware that deep change can be effected when people with learning disabilities support one another. A recent ‘Death Café’² for people with learning disabilities was organised by Victoria Mason, allowing just this to happen for a number of people with learning disabilities in the South West; people’s parents, support workers and/or personal assistants can also provide valuable support for people with learning disabilities. There is often a strong presumption of ‘professional’ hierarchy and therefore power, which does not acknowledge adequately the other players in the lives of people with learning disabilities.

² At a Death Cafe people drink tea, eat cake and discuss death. The aim is to increase awareness of death to help people make the most of their (finite) lives. - See more at: <http://deathcafe.com/#sthash.opTOhq6s.dpuf>

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4 In the therapeutic literature, those providing everyday support to people with learning
5 disabilities, support workers and personal assistants (PAs), are sometimes
6 mentioned only in the context of being part of the problem. They are not seen as
7 highly skilled and knowledgeable individuals who provide personal and emotional
8 support to people with learning disabilities on a daily basis, and who can also
9 support any therapeutic intervention outside of the therapy setting. This omission is
10 a widespread issue in much of the research literature, and reflects some tensions in
11 practice. Support workers and PAs are not widely seen as being valuable sources of
12 knowledge as they rank fairly low down on the 'professional' hierarchy, and have
13 relatively low-paid jobs.
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22 A number of studies based on recordings of naturally occurring interactions (e.g.,
23 Antaki *et al.*, 2007) have explored conversations between people with learning
24 disabilities and their support workers (Williams, 2011), and as mentioned this is also
25 one of the focal points for 'change' in our current study, 'Getting Things Changed'.
26 However, little work has been done to explore the knowledge and skills used by
27 support workers and/or PAs in their counselling and therapeutic roles. A PhD study
28 currently being completed by the first author, Victoria Mason, has attempted to begin
29 filling this void by exploring how support workers and PAs 'do' bereavement support
30 for people with learning disabilities. Co-working with a small group of people with
31 learning disabilities who have taken an active role in shaping the study, Mason has
32 found that support workers were grateful to have the time, space and respect from
33 another to talk about their work, exploring in great detail how they have provided
34 tailored and compassionate support to individuals at some of the most difficult times
35 in their lives. Yet they also expressed concern that they would be seen as being
36 'unprofessional' in these actions, although feeling in many ways they still had not
37 done enough for the person they were supporting. The professional literature (Skills
38 for Care, 2013) rightly creates and supports the construct of 'professional conduct'
39 amongst support workers, but that construct is sometimes used in common parlance
40 to create risk averse cultures, where professionals are assumed to keep an
41 emotional distance from the people they support. Mason's findings highlight the shift
42 of outlook that needs to take place both within learning disability services and the
43 wider 'professional' world towards support workers and PAs, who are valuable and
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knowledgeable members of the workforce providing both emotional and personal support to individuals, without doing harm to themselves or those they support.

People with learning disabilities can and do support each other, and are active agents in determining their own lives. Good talking therapies acknowledge that sense of agency, and more knowledge is needed now about how those therapies can be shaped to include people on an equal basis, so that we do not further pathologize a group of people who for too long have been objects of the medical gaze.

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